Helping Youth with Mental Health Needs Avoid Transition Cliffs: Lessons from Pioneering Transition Programs Issue 24, June 2009

This **InfoBrief** discusses challenges faced by youth and young adults with mental health needs during their transition to adulthood and describes strategies used by youth service professionals to avoid age-related transition cliffs and prevent service interruptions during this critical stage of development. This **InfoBrief** is based on a rich body of research about transition-age youth with mental health needs published in four separate reports in the last two years, including two produced by the National Collaborative on Workforce & Disability for Youth (NCWD-Youth).

While the transition from adolescence to adulthood is challenging for all young people, it can be especially difficult for youth with mental health needs who often face unemployment, underemployment, and discrimination when they enter the workforce. Adding to these challenges, youth with mental health needs often find it difficult to find or maintain services they need to successfully transition to adulthood including mental health treatment, employment and vocational rehabilitation, and housing.

According to the U.S. Government Accountability Office (2008), approximately 2.4 million young adults ages 18 to 26, 6.5 percent of non-institutionalized individuals in this age range, had a serious mental illness in 2006. The number of young people with mental health needs is expected to be much higher if those who are homeless, institutionalized, incarcerated or undiagnosed were also accounted for in researchers' estimates. This group has significantly lower rates of high school completion and postsecondary education compared to other individuals their age without serious mental illness.

Youth service professionals that encounter youth with mental health needs, whether in the education, vocational rehabilitation, workforce development, mental health, or another public system, are often the ones to identify the unique transition needs of youth and young adults during the transition to adulthood. Youth service professionals have a critical role to play in helping young people during this stage of development because no coordinated system currently exists to guide young people with and without mental health needs through the challenging task of entering adulthood. They can help young people navigate their way through the various uncoordinated service tunnels and avoid transition cliffs, and connect them to people and needed supports even if local programs do not yet formally offer transition programs. In some cases, their efforts will ultimately lead to the creation of transition programs.

To be effective in their role as navigators and supporters, it is imperative that youth service professionals know what youth need in order to succeed in the transition process. NCWD/Youth, a national technical assistance center, in collaboration with the U.S. Department of Labor's Office of Disability Employment Policy (ODEP), created the Guideposts for Success (http://www.ncwd-youth.info/content/guideposts-success), a comprehensive framework that identifies what all youth, including youth with

disabilities, need to succeed during the critical transition years. The "Guideposts for Success for Youth with Mental Health Needs," which incorporate all of the elements of the original Guideposts as well as additional specific needs relating to youth with mental health need, is a valuable resource for youth service professionals who seek to provide young people with an intentional, integrated, well-coordinated, and comprehensive set of services and supports.

Table: Guideposts For Success For Youth With Mental Health Needs

1. School-Based Preparatory Experiences

Specific Needs

In order to perform at optimal levels in all education settings, all youth need to participate in educational programs grounded in standards, clear performance expectations and graduation exit options based upon meaningful, accurate, and relevant indicators of student learning and skills. These should include

- academic programs that are based on clear state standards;
- career and technical education programs that are based on professional and industry standards;
- curricular and program options based on universal design of school, work and community-based learning experiences;
- learning environments that are small and safe, including extra supports such as tutoring, as necessary;
- supports from and by highly qualified staff;
- access to an assessment system that includes multiple measures; and
- graduation standards that include options.

In addition, youth with disabilities need to

- use their individual transition plans to drive their personal instruction, and strategies to continue the transition process post-schooling;
- access specific and individual learning accommodations while they are in school;
- develop knowledge of reasonable accommodations that they can request and control in educational settings, including assessment accommodations; and
- be supported by highly qualified transitional support staff that may or may not be school staff.

Because of the episodic nature of mental health disabilities, youth with mental health needs require educational environments that are flexible and stable and that provide opportunities to learn responsibilities and become engaged and empowered. These youth may need additional educational supports and services such as

• comprehensive transition plans (including school-based behavior plans) linked across systems, without stigmatizing language, that identify goals, objectives,

- strategies, supports, and outcomes that address individual mental health needs in the context of education;
- appropriate, culturally sensitive, behavioral and medical health interventions and supports;
- academically challenging educational programs and general education supports that engage and re-engage youth in learning;
- opportunities to develop self-awareness of behavioral triggers and reasonable accommodations for use in educational and workplace settings; and
- coordinated support to address social-emotional transition needs from a highly qualified, cross-agency support team (e.g., wraparound team), which includes health, mental health, child welfare, parole/probation professionals, relevant case managers, and natural supports from family, friends, mentors, and others.

2. Career Preparation & Work-Based Learning Experiences

Specific Needs

Career preparation and work-based learning experiences are essential in order for youth to form and develop aspirations and to make informed choices about careers. These experiences can be provided during the school day or through after-school programs and will require collaboration with other organizations. All youth need information on career options, including

- career assessments to help identify students' school and post-school preferences and interests:
- structured exposure to postsecondary education and other life-long learning opportunities;
- exposure to career opportunities that ultimately lead to a living wage, including information about educational requirements, entry requirements, income and benefits potential, and asset accumulation; and
- training designed to improve job-seeking skills and work-place basic skills (sometimes called soft skills).

In order to identify and attain career goals, youth need to be exposed to a range of experiences, including

- opportunities to engage in a range of work-based exploration activities such as site visits and job shadowing;
- multiple on-the-job training experiences, including community service (paid or unpaid), that is specifically linked to the content of a program of study and school credit;
- opportunities to learn and practice their work skills ("soft skills"); and
- opportunities to learn first-hand about specific occupational skills related to a career pathway.

In addition, youth with disabilities need to

- understand the relationships between benefits planning and career choices;
- learn to communicate their disability-related work support and accommodation needs; and

• learn to find, formally request, and secure appropriate supports and reasonable accommodations in education, training, and employment settings.

Because some youth with mental health needs may feel their employment choices are limited or may not understand the value of work in recovery, they need connections to a full range of youth employment programs and services such as

- graduated (preparatory, emerging awareness, proficient) opportunities to gain and practice their work skills ("soft skills") in workplace settings;
- positive behavioral supports in work settings;
- connections to successfully employed peers and role models with mental health needs;
- knowledge of effective methods of stress management to cope with the pressures of the workplace;
- knowledge of and access to a full range of workplace supports and accommodations such as supported employment, customized employment, job carving, and job coaches; and
- connections as early as possible to programs and services (e.g., One-Stop Career Centers, Vocational Rehabilitation, Community Rehabilitation Programs) for career exploration provided in a non-stigmatizing environment.

3. Youth Development & Leadership

Specific Needs

Youth development is a process that prepares young people to meet the challenges of adolescence and adulthood through a coordinated, progressive series of activities and experiences which help them gain skills and competencies. Youth leadership is part of that process. In order to control and

direct their own lives based on informed decisions, all youth need the following:

- mentoring activities designed to establish strong relationships with adults through formal and informal settings;
- peer-to-peer mentoring opportunities;
- exposure to role models in a variety of contexts;
- training in skills such as self-advocacy and conflict resolution;
- exposure to personal leadership and youth development activities, including community service; and
- opportunities that allow youth to exercise leadership and build self-esteem.

Youth with disabilities also need

- mentors and role models including persons with and without disabilities; and
- an understanding of disability history, culture, and disability public policy issues as well as their rights and responsibilities.

Some youth with mental health needs may be susceptible to peer pressure, experiment with antisocial behaviors or illegal substances, and/or attempt suicide as a manifestation of their disability and/or expression of independence. To facilitate positive youth development and leadership, these youth need

- meaningful opportunities to develop, monitor, and self-direct their own treatment, recovery plans, and services;
- opportunities to learn healthy behaviors regarding substance use and avoidance, suicide prevention, and safe sexual practices;
- exposure to factors of positive youth development such as nutrition, exercise, recreation and spirituality;
- an understanding of how disability disclosure can be used pro-actively;
- an understanding of the dimensions of mental health treatment including medication maintenance, outpatient and community-based services and supports;
- an understanding of how mental health stigma can compromise individual health maintenance and appropriate engagement in treatment and recovery;
- continuity of access to and an understanding of the requirements and procedures involved in obtaining mental health services and supports as an independent young adult;
- strategies for addressing the negative stigma and discrimination associated with mental health needs including cultural, racial, social, and gender factors;
- opportunities to develop meaningful relationships with peers, mentors, and role models with similar mental health needs;
- exposure to peer networks and adult consumers of mental health services with positive treatment and recovery outcomes;
- social skills training and exposure to programs that will help them learn to manage their disability/ies; and
- opportunities to give back and improve the lives of others, such as community service and civic engagement.

4. Connecting Activities

Specific Needs

Young people need to be connected to programs, services, activities, and supports that help them gain access to chosen post-school options. All youth may need one or more of the following

- mental and physical health services;
- transportation;
- tutoring;
- financial planning and management;
- post-program supports thorough structured arrangements in postsecondary institutions and adult service agencies; and
- connection to other services and opportunities (e.g., recreation, sports, faith-based organizations).

In addition, youth with disabilities may need

- acquisition of appropriate assistive technologies;
- community orientation and mobility training (e.g., accessible transportation, bus routes, housing, health clinics);
- exposure to post-program supports such as independent living centers and other

- consumer-driven community-based support service agencies;
- personal assistance services, including attendants, readers, interpreters, or other such services; and
- benefits-planning counseling including information regarding the myriad of benefits available and their interrelationships so that they may maximize those benefits in transitioning from public assistance to self-sufficiency.

Some youth with mental health needs may require a safety net accepting of the boundary pushing that is part of identity development and may include additional and more intense connections to information, programs, services, and activities that are critical to a successful transition. These youth may need

- an understanding of how to locate and maintain appropriate mental health care services, including counseling and medications;
- an understanding of how to create and maintain informal personal support networks;
- access to safe, affordable, permanent housing, including options such as transitional and supported housing;
- access to flexible financial aid options for postsecondary education not tied to full-time enrollment;
- policies and service practices that provide a safety net for fluctuations in a youth's mental health status;
- case managers (e.g., health care, juvenile justice, child welfare) who connect and collaborate across systems; and
- service providers who are well-trained, empathetic, and take a holistic approach to service delivery.

5. Family Involvement & Supports

Specific Needs

Participation and involvement of parents, family members, and/or other caring adults promote the social, emotional, physical, academic, and occupational growth of youth, leading to better post-school outcomes. All youth need parents, families, and other caring adults who have

- high expectations that build upon the young person's strengths, interests, and needs and fosters their ability to achieve independence and self-sufficiency;
- been involved in their lives and assisting them toward adulthood;
- access to information about employment, further education and community resources;
- taken an active role in transition planning with schools and community partners; and
- access to medical, professional, and peer support networks.

In addition, youth with disabilities need parents, families, and other caring adults who have

• an understanding of their youth's disability and how it affects his or her education, employment, and/or daily living options;

- knowledge of rights and responsibilities under various disability-related legislation;
- knowledge of and access to programs, services, supports, and accommodations available for young people with disabilities; and
- an understanding of how individualized planning tools can assist youth in achieving transition goals and objectives.

Youth with mental health needs also need parents, families, and/or other caring adults who

- understand the cyclical and episodic nature of mental illness;
- offer emotional support;
- know how to recognize and address key warning signs of suicide, the cooccurring relationship between substance abuse and mental health needs, and other risky behaviors;
- monitor youth behavior and anticipate crises without becoming intrusive;
- understand how the individualized plans across systems can support the achievement of educational and employment goals;
- access supports and professionals to help navigate the interwoven systems such as mental health, juvenile justice, and child welfare;
- access supports and resources for youth with mental health needs, including emergency contacts and options for insurance coverage;
- extend guardianship past the age of majority when appropriate; and
- have access to respite care.

(End of Table)

Service discontinuity is a significant challenge for youth and young adults with mental health needs. While various public systems offer services for individuals with mental health needs, it is common practice to divide service systems into those for children and those for adults. As a result, a young person being served by the child mental health system will eventually "age out" when they surpass the upper limit of the system's age defined eligibility criteria which may range from age 18 to 21. The child agency typically discontinues services to a young person who has aged out and refers him/her to the adult system. While services offered by the child agency may no longer match the young person's needs related to transitioning to adulthood, the adult system may also be poorly suited to the needs of individuals entering young adulthood.

A 2007 study, conducted by Maryann Davis for the Substance Abuse and Mental Health Services Administration Center for Mental Health Services, examined the problem of service discontinuity experienced by youth with mental health needs. As Davis explains, "for some youth, their condition does not qualify them for access to adult mental health services resulting in loss of services. For others, continuing on in adult services means a change of case manager (child to adult case manager), a change of therapist (their therapist is at a child community mental health center, not at the adult community mental health center), a change of residence (from an adolescent residential setting to an adult group home), a change of treatment culture (from more family and child focused to more

independent adult focused), a change of daily contact with peers (from hanging out with other adolescents in a day treatment program to being surrounded by mostly 35-50 year olds in an employment program), and other types of changes. These types of discontinuities interrupt service and program content, social environments, and attachments. It is likely that this kind of discontinuity leads eligible youth to reject services, or to struggle to adjust to them."

Davis identified seven programs, one state grant initiative and one federal grant initiative that have successfully reduced service discontinuity and established age-appropriate transition services for youth with mental health needs. These "pioneering" transition programs and grants include:

- Community Connections in Canton, Ohio
- Community Outreach through Resources and Education (CORE) in Westmoreland County, Pennsylvania
- Jump on Board for Success (JOBS) in Burlington, Vermont
- Program in Assertive Community Treatment (PACT) in Madison, Wisconsin
- Successful Employment Program in Quincy, Massachusetts
- Transition Community Treatment Team in Columbus, Ohio
- Westchester Youth Forum in Westchester, New York
- Transition Age Youth Initiative, a grant program of Maryland's Department of Health and Mental Hygiene
- Partnerships for Youth Transition grant, a program of the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration in partnership with the U.S. Department of Education

Through creativity and cooperation, youth service professionals and organizations created "pioneering" transition programs offering a range of transition services from education and employment to independent living and housing to youth and young adults continuously during the transition years, preventing service disruptions and benefit loss at a critical stage of development. Davis' case studies of pioneering transition programs offer the following guidance to other youth service professionals interested in developing similar programs in their area:

1) Recognize the problem and take action.

In Columbus, Ohio, the county Alcohol, Drug, and Mental Health Board and the county cluster (an interagency group) of child services agencies both saw a need to implement transition services for adolescents with severe mental health needs who were aging out of child services. A careful review of youth cases indicated many were bouncing from one system and placement to another during adolescence and eventually being admitted to a psychiatric hospital. At the same time, the adult system was struggling to meet the needs of young adults. Once the problem was identified, the county child and adult mental health system agreed to each contribute some funds to establish a transition community

treatment team to serve young people ages 16 to 22.

2) Become a leader.

The Community Connections program in Canton, OH, was established when staff of one community service agency sought and received a combination of private and state grants to continue serving transition age youth after a federal transition grant had ended. Although prior efforts to secure funding from county mental health agencies were unsuccessful, two youth service professionals persisted in their appeals to agency leaders and searched for other funding opportunities until a solution was found.

3) Involve other stakeholders.

The Successful Employment Program (SEP) in Quincy, MA, initially started with funding from the local Department of Mental Health to provide vocational and social support services to 16- to 18-year-olds with mental health needs. When the SEP coordinators heard the vocational rehabilitation system was struggling to meet the needs of some young adults over age 18, they proposed to the local VR agency that they pay for slots for their 19- to 22-year-old clients to participate in SEP's work related services and supports. As a result of the successful collaboration between the mental health and VR agencies, SEP eventually received approval from the Department of Mental Health to extend services funded by the mental health system to young people up to age 22.

4) Extend local expertise and experience to design the program.

The Community Outreach through Resources and Education (CORE) program in Westmoreland County, PA, was designed collaboratively by an interagency taskforce convened by the county mental health system. Because it was a collaborative effort, the program design was informed by the collective expertise of professionals working in mental health, education, juvenile probation, child welfare, vocational rehabilitation, mental retardation, child and family services, drug and alcohol services, and advocacy groups. Together, the taskforce members wrote the funding proposal that the county mental health agency submitted for a state mental health agency grant. Once the grant was awarded, the taskforce selected one of its members, Family Services of Westmoreland County, to provide the services because the organization already had expertise in vocational and case management services for child and adults and was well connected to other resources in the target community.

5) Seek funding through trusting relationships.

The youth service professionals who started Jump on Board for Success (JOBS) program in Burlington, VT, leveraged their already positive relationship with the state vocational rehabilitation office to obtain an initial grant for a combination of supported employment and wrap around services for 16 to 22 year olds with serious mental health needs. The two service agencies that made the funding request had strong track records in the eyes of VR – Green Mountain Work Force did great work with adults with serious mental illness

and Washington County Mental Health Services already had a successful wrap around program for youth under age 18. Together, staff of both organizations developed a proposal to merge the wrap around approach with supported employment services for transition age youth. Letters of support from the local child welfare agency and other providers helped to convince VR officials that the proposal would meet critical local needs.

6) Start small and build funding over time.

The Westchester Youth Forum started out with a meager \$10,000 grant from the regional child Office of Mental Health by arguing that the youth-led program corresponded with family support programming, thus making it a suitable use of family support funds. Over time, the Forum became recognized as an integral part of the system of care and subsequently received additional funding through the Youth Bureau and from the county mental health agency's federal system of care grant.

7) Seek mental health funding primarily from either the child or the adult system, not both.

While the pioneering transition programs studied typically relied on a combination of funding sources, funding they received from the mental health system was either from the adult mental health service system or the child mental health service system, not both.

Engage Youth and Families as Leaders, Decision Makers, and Designers

One of the case studies provides an exemplary model of active youth involvement. The Westchester Youth Forum (WYF), Westchester, NY, stands apart as a youth-led initiative. WYF was developed through the collaborative effort of young people from a family mental health advocacy group and staff of the advocacy group and the county child mental health agency. With support from social workers, several youth wrote a report detailing their experiences as consumers and recommendations for improving services and opportunities for youth. The organizations hosted a forum in which the youth presented their report to leaders from each county agency (social services, developmental disabilities, substance abuse, probation), the schools, and other local decision makers. Following this meeting, the advocacy organization agreed to provide some funding for staff to support the youth leaders in forming peer support groups and organizing recreational and social activities for youth ages 16 to 23. Initially, the county child mental health agency provided in-kind support to the staff and the youth held fundraisers to support their activities. Eventually, the youth-led program became a part of a local mental health service provider agency and the county obtained a small grant to support the program's staff and activities. The regional Office of Mental Health agreed to provide the grant using family support funds from its child mental health budget.

Build Upon Knowledge of What Works for Youth with Mental Health Needs

While many of the "pioneering" transition programs reported lacking information on best practices in serving transition age youth when they were starting up, many resources are now available to youth service professionals to guide program design and implementation. In addition to the *Guideposts for Success for Youth with Mental Health Needs*, NCWD/Youth in collaboration with ODEP developed the following guidance for youth service professionals:

Successful Transition Models for Youth with Mental Health Needs: A Guide for Workforce Professionals, an InfoBrief issued in May of 2009 available at http://www.ncwd-youth.info/information-brief-23

Navigating Tunnels & Cliffs: Empowering Families and Caregivers to Assist Youth with Mental Health Needs in Preparing for Work, a May 2008 publication available at http://www.ncwd-youth.info/short-cut/navigating-tunnels-and-cliffs

Tunnels & Cliffs: A Guide for Workforce Development Practitioners and Policymakers Serving Youth with Mental Health Needs, a May 2008 publication available at http://www.ncwd-youth.info/short-cut/tunnels-and-cliffs

Tunnels & Cliffs: A Guide for Workforce Development Practitioners and Policymakers Serving Youth with Mental Health Needs, a 2007 comprehensive guide available online at http://www.ncwd-youth.info/tunnels-and-cliffs

Transitioning Youth with Mental Health Needs to Meaningful Employment & Independent Living, a 2008 publication available online at http://www.ncwd-youth.info/white-paper/transitioning-youth-with-mental-health-needs

For more information on issues related to youth with mental health needs and/or professional development for youth service professionals, please contact the National Collaborative on Workforce and Disability for Youth at http://www.ncwd-youth.info.

References

Davis, M. (2007). Pioneering Transition Programs: The Establishment of Programs that Span the Ages Served by Child and Adult Mental Health. Rockville, MD: Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

Podmostko, M. (2007). *Tunnels & Cliffs: A Guide for Workforce Development Practitioners and Policymakers Serving Youth with Mental Health Needs.* Washington, D.C.: National Collaborative on Workforce and Disability for Youth, Institute for Educational Leadership.

U.S. Government Accountability Office, Report 08-678 (2008). Young Adults with Serious Mental Illness: Some States and Federal Agencies are Taking Steps to Address Their Transition Challenges. Washington, D.C.

Woolsey, L., & Katz-Leavy, J., (2008). *Transitioning Youth With Mental Health Needs to Meaningful Employment & Independent Living*, Washington, DC: National Collaborative on Workforce and Disability for Youth, Institute for Educational Leadership

The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) is composed of partners with expertise in disability, education, employment, and workforce development issues. NCWD/Youth is housed at the Institute for Educational Leadership in Washington, DC. The Collaborative is charged with assisting state and local workforce development systems to integrate youth with disabilities into their service strategies. This Information Brief was written by Mindy Larson.

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